Autistisch gezelschap

Summary

Autistic Company
An empirical-philosophical study of the shared existence of autistic and non-autistic persons

Autistic Company is concerned with the nature of social interactions between autistic and non-autistic persons. The vocabulary, which allows one to adequately represent these interactions, is also at issue. The combination of empirical and philosophical research that characterises this book has a conceptual purpose: The study aims to enrich the repertoire of words and images that can be used to draw the reader's attention to the shared existence of autistic and non-autistic people. It is argued that this study does not only expose the intricacies of exceptional cases of society-in-the-making, but also throws new light on what is usually taken for granted with respect to the nature of the community of people-among-themselves.

In chapter one some relevant aspects of the object under study are brought to the fore by looking at popular imagery around autism. Narratives about the autistic person as (noble) savage or man-machine are understood to show that in dealing with autistic persons one cannot rely upon ordinary ways of mutual fine-tuning. Compared to the ordinary course of events, getting along with autistic persons is so different, that one may seriously wonder whether the term 'interaction' is appropriate at all. On the other hand, in all kind of situations (at home, at school, at work), people with autism take part as a matter of course in the daily life of their non-autistic surroundings. How can this be? What alternative means is available in this case? What kind of work is required to extend commensality and by whom is it performed?

In order to discuss interactions of autistic and non-autistic persons, and to acknowledge its self-evident as well as extraordinary nature, there is a second matter of importance: One should mind one's words. Stereotypical stories, in which autistic persons are likened to puppets and machines, can be traced back to a deep-rooted differentiation between the human sphere and the material world. Philosophers (e.g. Sartre and Wittgenstein) also describe the everyday-character of this human/thing dichotomy. In the case of autism, however, the dividing-line between people and things seems problematic. Autistic people may even risk finding themselves on the wrong side, among the material world of things.

The mechanistic metaphors used to describe autistic people can be taken to indicate that in the case of autism we are dealing with a way of being that is radically different from what people usually hold as their own. On the other hand, mechanistic metaphors seem to widen the gap between us and them unnecessarily, and seem not to do justice to the ways in which autistic and non-autistic persons manage to live together – situations in which dichotomies may indeed, but need not be found. To do justice to the complex nature of the object under study, the conceptual barrier of the dualism of people and things must be cleared away without, however, doing away with the everyday reality of that same divide.

Before elaborating these matters, in chapter two factual information about the autistic disorder, without which the present-day fascination with autism can hardly be understood, is presented. First, early studies of autism are used to discuss historical developments in the classification and diagnosis of the autistic (spectrum) disorder. According to the *DSM-IV* classification, autism is characterised by a qualitative impairment in the social, communicative and imaginative abilities, and restricted, repetitive, stereotypical patterns of behaviour, interest and activities. Next, the nature of these impairments is further described, with special attention for the dynamics and diversity within the triad of social impairments. Under the heading 'explanations', nurture-approaches of autism (which are nowadays dismissed) are discussed, as well as the rise of approaches, which seek to explain autism as an inborn defect. Finally, chapter two briefly goes into the counselling of autistic persons, and the tension between the (humanistic) ideal of personal development on the one hand, and the need to provide a structured surrounding on the other apparent here.

In chapter three, the Dutch novel *Vallende ster* (published in English as *Shooting Star*) by J. Bernlef (1989) is analysed in order to facilitate further discussion of interactions between autistic and non-autistic persons. The focus is on the conceptual innovation concealed in Bernlef's novel. Employing a semiotic vocabulary, borrowed from among others the work of Latour, *Shooting Star* is read as an effort to re-present the shared existence of autistic and non-autistic people, without relapsing into a traditional, epistemological gap between subject and object. Bernlef begins by using the aforementioned dichotomy of people and things to evoke both the non-autistic perspective and the autistic situation. But instead of offering (epistemological) 'insight', Bernlef – by employing a literary technique, that of shifting out in character, time and place – offers a means of transport which allows his reader to visit (fictional) situations which are (or so Bernlef suggests) increasingly further removed from our familiar, non-autistic existence.

In this thesis, a similar vocabulary and means of transport are used to bring non-fictional situations into the reader's reach. The three case studies following upon this chapter are first described using a non-autistic frame of refe-

rence the reader is supposed to be familiar with. Next, in order to prevent a familiar, non-autistic interpretation from thoroughly biasing our understanding of the joint existence of autistic and non-autistic persons, we will gradually remove ourselves from our point of departure. These conceptual tools will allow me to indicate the kind of situations, which are exemplary for the interactions of autistic and non-autistic persons we are concerned with. Each case study focuses on one of the core-symptoms of the autistic disorder. Thus, impairments and solutions in the realm of imagination, socialisation, and communication will be focused upon successively in chapters four, five, and six.

Chapter four is concerned with the role of imagination in social interactions and play-behaviour. First, the difficulties autistic persons have in the realm of imagination, in mentally 'going beyond' the concrete and immediately given is described. The impairment in social imagination and understanding is then explained in cognitivist terms, as impairment in meta-representation and in the development of a *theory of mind*. This cognitive-psychological explanation depends upon a simulation of the dualist world on laboratory-scale, against which the monistic (behaviouristic or mechanistic) worldview of autistic persons appears as deviant. However influential, critics hold that the theory of mind approach is not as watertight as proponents might have it. Whereas from this perspective non-autistic people proceed with intuitive ease, some high-functioning autistic people still seem to be able to compensate for their empathic impairment, by employing a slow and formal cognitive detour. Most autistic persons, however, are unable to compensate by force of thought. Must we then conclude that there is no place for imagination in the life of (and with) the majority of the autistic population?

In order to answer this question it is necessary to distance ourselves from a cognitivist perspective on (the role of) imagination in social interaction and play. Thus, reports of practice-oriented researchers, counsellors and autistic persons are analysed for their alternative ways of conceptualising imagination. All kinds of practical solutions, of 'mind-crutches', are shown to be able to correct the rigid cognitive style of autistic persons, without relying on intellectual *tours de force*. These ways are also accessible for those who lack the intellectual capacities to compensate their lack of theory of mind by logical reasoning. The extra-mental forms of imagination which are explored in this chapter, however deviant from what can be imagined within non-autistic frames of reference, reveal a specific autistic talent or capacity for imagination.

Chapter five is concerned with socialisation in a ward for mentally handicapped autistic youths (where ethnographic research was done). The chapter focuses on problems confronting counsellors in the ward when processes of socialisation falter, especially the temporal ordering of social life. During mealtimes, for instance, people working and living in the ward see themselves obliged to explore unusual ways of fine-tuning to one another's expectations and

behaviour. Instead of relying upon an implicitly shared understanding of what it means to share a meal in an 'appropriate' way, mechanistic aids (such as an egg timer) are applied in order to secure a sociable atmosphere among the table companions. In their way of working, it thus becomes apparent that counsellors have learned to free themselves from familiar, non-autistic values and habits. As soon as they start to reflect upon their work, however, it appears more difficult to avoid dualistic clichés. In their appraisal of the humanistic ideals far removed from daily life in the ward, versus the (reductionist) mechanistic means closer at hand, the dualism, which we are trying to escape, still looms.

Therefore the second part of this chapter seeks to distance our understanding of achievements in the ward still further from familiar interpretations than the counsellors themselves already do. Instead of taking their stories and interpretations as a starting point for analysis, the mechanistic 'means' counsellors talk about are put centre-stage. These unobtrusive objects become the 'narrative nodes' around which other elements revolve. Such an estranging description of life in the ward focuses on socialisers, which would normally remain invisible. This is especially true for processes of temporal ordering which partly escape the stories of counsellors, and do not fit neatly into their dichotomy of (good) intentions and (poor) means. The achieved distance with respect to familiar interpretations reveals the existence of object-centred forms of sociality, which might be better adapted to what autistic participants value in a shared existence.

Chapter six is concerned with the question what autobiographical texts by autistic authors can teach us about communication, especially language, in the shared existence of autistic and non-autistic persons. After a brief look at the communicative minority among the autistic population, the 'auti-biography' is first considered as offering another, 'autistic' perspective on the shared existence. According to this perspective, concrete structures and the material qualities of the world play a pivotal role in the lives of autistic people. This observation, however, leads to a paradox with respect to the status of the (autobiographical) text itself. The lucid and flexible language-use of the author seems itself to escape the very desire for repetition and problems with meaning that the author is describing. An analysis of the way this paradox is normally dealt with, reveals that we are tempted over and over again to interpret the extraordinary achievement of the autistic author in ways much too ordinary.

In the last part of this chapter it is therefore attempted to further distance our understanding of the role of language from familiar interpretations. Instead of considering the text as a window, as a symbolical reference to a reality outside, the material quality of the text itself is explored. Instead of explaining the paradox away by trying to turn the author into a normal, meaningful, non-autistic user of language, the reverse move is made. The attempt is made to meet the autistic need for concrete order by absorbing the autistic preference for form,

colour, taste, and other material qualities, in our conceptualisation of language itself. Thus it becomes clear how the autistic author appreciates other than meaningful aspects of the language we share.

In chapter seven, the conclusion of the thesis, first some crucial aspects of the non-autistic self-image that have so far remained implicit are discussed. The outcome of normal social-cognitive maturation, the way in which this outcome is usually achieved, and the ideals that remain intact even when the essential preconditions of a normal development are not fulfilled (which seems to be the case in autism), are described. This self-description suggests that *we*, at least, are taken care of: we are sociable beings by nature, distancing ourselves from the material world is child's play to us, we feel at home in the meaningful world of people-among-themselves. It is the self-evidence of precisely this presupposition that is questioned in this study. The image of the non-autistic person as a sociable being may partly be defined in contrast with another, autistic way of being, but my analysis of interactions of autistic and non-autistic persons shows that this (idealised) self-image should be amended.

In interactions with autistic persons we appear to be other people than we tend to think we are. Retrospectively, the non-autistic self-image can be amended in three respects. First, as far as the outcome of a shared existence is concerned, a term such as 'community of people-among-themselves' falls short. Rather, we need a concept of sociality that is heterogeneous enough to encompass the rich assortment of elements and their various mutual relations which make up the social world. The creation of such a heterogeneous community, second, does not proceed spontaneously and without effort, as the cliché has it, but is a laborious process. Paradoxically, in the process, a lot of effort goes into delegating tasks to other, maybe more unlikely members of the social body, such as the world of material objects. The ideal of a shared existence, finally, is still characterised by a desire to keep one another company, with social recognition, communication and imagination as the cornerstones, be it in an adapted way. In interactions of autistic and non-autistic persons, social abilities and impairments – which are normally held to part ways along the line non-autistic/autistic – are redistributed among the members of the community. Lastly, this offers an interesting perspective on what remains hidden, what goes without saying, in the way non-autistic people are trying to keep *each other* company.